

Consilience: The Journal of Sustainable Development
Vol. 7, Iss. 1 (2012), Pp. 87-96

Disability is Not Inability: Grassroots Participatory Development and Collective Action in the Iganga District of Uganda

Daniel Alamillo

School of Culture, Education and Human Development
New York University

DanielAlamillo@gmail.com

Lilia Diaz

School of Culture, Education and Human Development
New York University

DiazLilia@gmail.com

Abstract

Development planners continue to use mainstreaming as a way to include marginalized groups in the international development agenda. However, grassroots programs are gaining increasing attention as they are proving to be more effective than top-down measures. Furthermore, participatory programs allow individuals and communities to actively participate in their own development. This paper analyzes how one particular community of people with disabilities in Uganda are actively playing a role in their own development, both through participatory programs and collective efforts. This paper chronicles the implementation of participatory forms of development by people with disabilities (PWDs) in the Iganga district of Uganda. The paper could potentially lay the foundations for further research on the ability of local actors to create social change, or “development,” through their own actions. Participatory programs/models like these could be included in the international development agenda to allow people to become active in their own development.

“Overlooking or ignoring the plight of disabled people is not an option that an acceptable theory of justice can have.” -Amartya Sen, 2004

“The per capita income for an average person in Iganga is \$312 while that of a disabled person is \$78.”¹

“An old Chinese proverb says ‘Give a man a fish, and he will eat for a day, but if you teach a man to fish, he will eat for a lifetime’” -Local Village Leader of the Busoga Kingdom, John Wamulo Sr.²

¹ IDIWA Pamphlet

² Interview on the day of June 7, 2011 at the Nakavale Village in Iganga, Uganda

1. Introduction

Thirty-year-old Hadija Nabirye was born into a world similar to that of many Ugandans: a family of thirteen, living on a small plot of land they were fortunate enough to own, surviving on the meager income the family managed to earn after a long day's work in the garden. As in many Ugandan households, Hadija's father abandoned the family. Less typical, the reason for his abandonment stemmed from the realization that his daughter, Hadija, would be disabled for the rest of her life. Cultural norms dictated that Hadija's father believe Hadija's mother was an inadequate wife because she bore a child who became disabled, and was possibly possessed by a demon. In reality, Hadija had not been immunized for polio and, as a result, had contracted the disease at the age of two. Polio ravished Hadija's body, paralyzing her from the waist down; she could only sit and watch as other children went to school. Because of a lack of medical treatment, Hadija's polio progressively worsened and by the age of four she regressed to crawling on her knees and elbows. Due to the lack of mobility she experienced, lack of funds available to her, and a general disinterest from her family, Hadija never attended school. Hadija's family was also severely affected when, at the age of fourteen, her younger brother suddenly "became mad." Though the boy has never received a proper diagnosis, he seems to display the symptoms of a paranoid schizophrenic and the family has been forced to simply accept his condition.

We were able to hear Hadija's story through a series of semi-structured interviews directed at assessing the needs of persons with disabilities (PWDs) in the Iganga District of Uganda. In an interview, Hadija expressed a strong desire to live independently and share the same opportunities as her peers. Her reality, however, required her aging mother to feed her, assist her in responding to nature's calls, lift her to access small stairs in the household, and drag her into the home when the rain turned dirt into mud and prevented Hadija from crawling. Her limited mobility kept her from having any semblance of a "normal" life. Though Hadija had only been taken out of her home a few times in thirty years, community members gradually learned about her severe disability and offered assistance when they could. Her mother would receive free tailoring services when the local tailor recognized the unconventional fit of the clothing and she would also often receive food and goods at discounted prices from the local market. The interview with Hadija was one of many interviews in which PWDs in Iganga identified self-reliance, employment, and equal opportunities as their greatest needs. However, important questions persisted: How could PWDs best improve their quality of life, particularly amidst seemingly insurmountable barriers like extreme poverty and cultural stigmatizations linked to disability? Moreover, how could PWDs work together to become self-reliant and obtain socio-economic upward mobility within their communities? Our research utilized theory and practical application to examine how grassroots organizing can help marginalized groups, such as PWDs, remove themselves from poverty and strive for social justice. Specifically, three community-based projects were implemented in the Iganga District to assess how community-based participatory collective action could help PWDs improve their lives, economically and socially.

2. Literature Review

People with disabilities (PWDs) suffer from an array of challenges throughout the world and, for the most part, are a marginalized group. In developing nations such as Uganda, PWDs are hindered by “chronic poverty” as well as social, economic, and political exclusionary actions that keep them on the fringes of society.³ Some development initiatives, such as *The Millennium Development Goals* (MDG’s), initially left people with disabilities out of the global development agenda, despite the fact that eighty percent of PWDs come from developing nations.⁴ At the top-down level, PWDs and advocates for the rights of PWDs are mainstreaming disability as part of development work by including the rights of PWDs in global initiatives and policies.⁵ However, like all development initiatives, work needs to be done at the grassroots level as well as through top-down avenues to best serve disadvantaged peoples and empower them effectively.

PWDs must be integrated into the economic system in an egalitarian way in order for them to overcome chronic poverty.⁶ Grassroots participatory forms of development have shown progress in uplifting people at the local level. Muhammad Anisur Rahman proposes participatory development (PD) and collective action as a way for the disadvantaged to liberate themselves from social marginalization. Rahman worked with the Grameen Bank and builds on Freirean principles such as “conscientization,” a deep understanding of the world and its contradictions that work to guide action against oppression.⁷ According to Rahman, Civil Development Agencies (CDA’s) should promote collective initiatives and focus on one locale rather than expanding themselves over vast regions while inculcating a self-reliance ethos. Community based organizations and community participation are crucial in emancipating PWDs from their marginalized economic, social, and political status. The community-based projects that were implemented utilized Rahman’s ideas of participatory development, collective action, and self-reliance, in an attempt to improve the quality of life and economic status of PWDs in the Iganga District of Uganda.

However, the cultural context must be considered when implementing development programs. In order to best serve a community, cultural practices, rituals, and beliefs should be respected and understood by development planners. Planners should not only understand local culture prior to applying development agendas, they should also understand how disability, specifically, is viewed by the

³ Lwanga-Ntale, Charles, *Chronic Poverty and Disability in Uganda*, International Conference at the University of Manchester, 2003.

⁴ International Convention on the Rights of Persons with Disabilities, 14-25 Aug. 2006, Enable! Factsheet.

⁵ <http://www.un.org/disabilities/default.asp?id=1470>

⁶ Yeo, Rebecca, *Disability, Poverty, and the New Development Agenda*, 2005.

⁷ Rahman, Muhammad Anisur, *Participatory Development: Toward Liberation or Co-optation*, Community Empowerment: A Reader in Participation and Development, 2008.

local culture.⁸ Coleridge propounds: “The way societies think about disabled people is determined by a variety of cultural variables, including the nature of the impairment.”⁹ He explains that is imperative for planners to not treat disability holistically; rather, they must learn about and understand how varying impairments are treated within the community. The aim of the projects implemented in various villages was to understand and respect cultural contexts to strengthen the identified development initiatives. In Uganda, PWDs tend to be marginalized and relegated to chronic poverty due to cultural norms, such as the “feminisation of disability,” which defines disabilities as a feminine quality and results in men blaming women for the disability of a child.

As previously mentioned, Paulo Freire’s concept of conscientization also played a crucial role in fulfilling our goal of improving the quality of life of marginalized PWDs. Freire defines conscientization as “the process in which, men, not as recipients, but as knowing subjects, achieve a deepening sense of awareness both of the socio-cultural reality that shapes their lives and of the capacity to transform that reality.”¹⁰ According to Freire, marginalized groups and individuals, such as PWDs, must become aware of their constraints and then actively participate in the removal of them. Our project used Freirean praxis in order to build community awareness and self-awareness around the challenges PWDs face and the perpetual inequalities engrained in Ugandan society and culture.

3. Research Methods

Data collection began June 1, 2011 and continued through the end of our internship with Integrated Disabled Women’s Activities (IDIWA) on July 23, 2011. To best understand Ugandan culture, we used translators and local residents to help guide and monitor our work and enlighten us on Ugandan practices and social norms. We conducted a needs assessment with PWDs from three local villages in three distinct sub-counties. In order to do so, we developed a semi-structured interview protocol that facilitated a better understanding of the challenges PWDs face and what they felt they most needed to improve their quality of life. Interviews were conducted with PWDs in the Iganga District of Uganda, leaders in the PWD movement, parents of children with disabilities, and the staff of two local NGOs that focus on improving the life and status of people with disabilities. Both men and women were interviewed, but, because IDIWA beneficiaries are mostly women, female interviewees outnumbered male. The duration of each individual interview ranged from approximately one to one and a half hours. After concluding twelve interviews, we held focus groups with three local village communities. Each focus group was approximately two hours in length and an abridged version of the semi-structured interview protocol was used for the focus groups.

IDIWA staff mobilized groups in Kinawanswa village within the Bulamagi Sub-County, and Nawansinge village within the Bukoyo Sub-County. Staff of Uganda

⁸ Coleridge, Peter, *Disability and Culture*, Disability KAR: Knowledge and Research.

⁹ Ibid.

¹⁰ Freire, Paulo, *Cultural Action and Conscientization*, Boston: Harvard Educational Review, 2000.

Parents of Children with Learning Disabilities (UPACLED) organized a group in the Bukyaye Village in the Nakalama Sub-County. Each of these villages are within the Iganga District of eastern Uganda and most of the people interviewed are beneficiaries of either IDIWA or UPACLED. Initially, convenience sampling was used: those interviewed were mobilized by the NGOs we were working with. However, these mobilized villagers brought other PWDs to participate in meetings, creating a snowball effect.

Observations were also made on a daily basis in different communities and at local NGOs. Finally, a school assembly was conducted to bring awareness to issues within the disabled community and, in general, the local community in Iganga, integrate themes of social justice and equality into the mindsets of individuals. Observations, individual interviews, focus groups, and a school assembly were used to direct our research and narrow our focus on how to best serve groups of PWDs at the local level through a participatory form of development.

4. Findings

4.1 The Wide Range of Disabilities

Through our research, we encountered people with a wide range of disabilities. Physical disabilities were most common amongst our participants and, for the most part, were a result of past experiences with a lack of access to adequate healthcare and/or a lack of faith in the local healthcare system. For example, one man in the Bukoyo Sub-County fell out of a tree when he was twelve years of age and believed he broke a few bones in his leg. He did not receive any treatment for his broken leg and now, at age forty-two, he has lived the past thirty years of his life without being able to move his leg and will be considered “lame” for the rest of his life. However, the large majority of individuals interviewed attributed their physical disabilities to a lack of immunizations or the maltreatment of common diseases and illnesses. We encountered many polio survivors who became physically disabled, or “lame,” because they were never immunized. Poor treatment of malaria also resulted in the paralysis of individual’s limbs. In addition, many women—particularly mothers—suffered from disabilities caused by complications when giving birth. Finally, a significant portion of participants never received a proper explanation regarding the causes of their disability. Many provided the simplest of explanations: “I fell sick and couldn’t move my leg anymore,” or “I was in the garden, my toes became extremely itchy, I went to the local clinic and they insisted they remove my toes,” or “I felt pain, then I couldn’t move the left side of my body.” While this data suggests a dire need for improvement in the Ugandan healthcare system and education about healthcare, our interviewees directed us to the immediate, urgent needs of those already affected by disabilities.

The wide range of disabilities, from physical to sensory to cognitive, directly impacts each individual’s livelihood and even appears to present divisions among the disabled community. For example, Babirye from Bulamagi Sub-County was unable to walk and had crawled through her entire fifty-two years of life. Her disability prevented her from attending school, leaving her village, and securing a consistent source of income. On the other hand, George from Bukoyo Sub-County lost his left

eye in an accident when he was eight years old. Though he had a visual impairment, his mobility was not affected and he was able to attend school. Presently, he is pursuing higher education at the local University where he studies Business Administration. Elizabeth Kayanga, Executive Director of IDIWA, implied that these differences in disability prove to divide the disabled community: “For many PWDs, some disabilities are not severe enough, like those who crawl feel every PWD should crawl.” Judith Nambia, a volunteer at IDIWA, was diagnosed with epilepsy in 2009 and echoed this sentiment. She stated, “My disability is inside, not outside, so some beneficiaries think I don’t understand what they are going through.” Income and levels of attained education also seemed to further divide the disabled community. Hanifah, an accountant at IDIWA who is hard of hearing, attended the prestigious Makerere University in Uganda, despite being forced to copy notes from other students’ notebooks immediately after she attended her lectures. Her education and status in her community seemed to help her overcome negative stigmas associated with her disability but may have simultaneously alienated her from the disabled community.

4.2 Needs of PWDs

Despite their differences, PWDs identified the same needs. Throughout our interviews and research, individuals emphatically emphasized that PWDs were a divided group that needed to build and nurture a sense of community. Kayanga asserted that NGOs, like IDIWA, are playing a vital role in bringing people with different disabilities together. In addition, IDIWA staff expressed the fundamental need of raising awareness around the plight of PWDs in Uganda. Organizations, like IDIWA, are sensitizing whole communities on the services available to PWDs in the district and the benefits of being part of a cohesive group. As a result, some PWDs acknowledged a sense of community and continue to work to improve and broaden the cohesion within PWDs of Iganga. Andrew Paul Wanyama, a polio survivor, believes, “I feel a sense of community with other PWDs because of my impairment, if I see a PWD, it’s like, oh, my brother.” Wanyama is currently in the process of registering a group of PWDs from his village as an official community-based organization (CBO) that is recognized by his sub-county. Wanyama recognized that, by forming a governmentally recognized group, they could mobilize together and potentially benefit from the few available government resources and training available to PWDs in Uganda. These include agricultural capital livestock or training to develop a constitution for a PWD “association” in Uganda. Wanyama’s knowledge opened our eyes to the benefits of forming community-based groups and the power of collective action.

Repeatedly, PWDs claimed that a lack of awareness around disability added to the cultural stigmas held against PWDs in Uganda. Faith Nampeera, IDIWA Project Coordinator, stated, “families often hide their children because it is very shameful for a family to have a child with a disability.” Judith Nambi also spoke of her personal experiences with her family, one who was ashamed of their daughter’s inexplicable epileptic seizures. Nambi explained that she could not live at home because of the abuse she regularly encountered from her family. Nambi still questions her family’s abuse: “I am still searching why my family doesn’t help me. I am only respected in

my family because I applied force upon my sister, since then she doesn't verbally abuse me. I prefer staying in town without my family and renting a room alone. I prefer that than going home." Kayanga went on to further explain common beliefs regarding the causes of disabilities, and the detrimental repercussions of those beliefs. She stated, "Unhelpful cultural beliefs hinder positive steps in addressing the plight of PWDs. For example, even if one clearly has polio, there is a belief that a demon causes the disability. If a child possesses a demon s/he cannot attend school because of the fear held by the local community." An eighteen year-old victim of poor malaria treatment, Franco, succinctly stated, "All of Africa thinks disabilities are from what? Witchcraft. To change that is important for Africa." Whether it is called a demon, or witchcraft, the cultural stigmas against PWDs are ever present in Iganga and awareness to promote the destruction of these stigmas is fundamentally necessary.

The repercussions of cultural beliefs are particularly exacerbated for women with disabilities. As a woman with a disability, Kayanga summarized that women with disabilities are often deprived of education, both formal education and informal education within the home. She stated, "Women are not trained to be a good woman because they are not expected to marry." While society expects all women to be prepared for marriage, those with a disability fail to gain the knowledge and skills necessary to fill their predetermined role. It is a challenge for women with disabilities to be accepted as wives. Kayanga explains what often happens to these women: "Men leave at dawn and leave behind HIV and pregnancy. These women tend to have large families and are forced to raise their children alone. I've seen a woman with more than seven children residing under a tree and still producing." PWDs that are women in Uganda face unique challenges in Uganda and this repeatedly came up in our research.

While overcoming cultural stigmas is vital for PWDs in Iganga, the most crucial need PWDs identified was the ability to generate income to sustain themselves. Mothers, fathers, grandparents and children alike reported a lack of income necessary to cover school fees, contribute to the family income, and fulfill their basic needs. However, a lack of mobility, restricted bodily functions, and cultural stigmas lead to a lack of education and a great challenge to perform valuable work and earn an income. Ronald, a blind man from Bulamagi Sub-County, was twenty-three years old and had never attended school. His visual impairment also prevented him from earning an income through agriculture, the most common income-generating activity in his village. Ronald depended on the local community for minimal support and believed the only way he could secure a source of income was if he obtained a musical instrument that he could play in town as he sought donations. Conducting individual interviews revealed that PWDs are an extremely diverse group, with different disabilities of varying intensities and with distinct limitations and skill sets. However, the desire to become self-reliant through an independent mode of earning income lay at the heart of all PWDs interviewed.

4.3 Community Based Activities

As previously mentioned, Wanyama's lessons regarding community collaboration resonated throughout our assessment of needs and three Iganga villages were

targeted to conduct focus groups. Each focus group, consisting of twenty-three to twenty-eight village members, revealed its specific needs and potential contributions to a community-based income generating activity. Kinawanswa villagers had experience in agriculture and animal husbandry and believed they could harvest groundnuts as a community to obtain a stable source of income together. Nawansinge villagers had similar experience and backgrounds, but many had also been trained in tailoring clothing and believed they would find success with a clothing retail store collective. In the Bukyaye village, poultry and cattle rearing was the most common source of income and the villagers believed that, with each other's support, they could divide the labor of poultry rearing to gain a consistent source of income. Each group came to a consensus about what project could most help them generate income as a community and assured they each had skills they could contribute to the collective. These projects were to allow each participant to be part of a community-based organization that required each of their skills and could provide them with a consistent source of income. While members shared their skills to collaborate on joint projects, the value placed in each individual and the potential for a consistent source of income gave each member the opportunity to become self-reliant, regardless of her/his disability.

As a result, we facilitated the creation of a community-based organization within each village. We attempted to support PWDs in their effort to generate income through collective action and community-building through grassroots organizing. After the initial meeting with each focus group, we facilitated four weekly meetings preceeded by six bi-weekly meetings to assist each group in developing their ideas and creating a plan of action. Meetings consisted of establishing a skills inventory of each group and determining how the list of collective skills would be utilized. In Kinawanswa the villagers developed a plan to collectively harvest and sell groundnuts; in Nawansinge a business plan was developed to build a second-hand clothing retail store where skilled members would also train each other on tailoring and clothing production for the benefit of the retail store; in Bukyaye a plan was developed to create a cooperative chicken coop. Recognizing their limitations, the villagers also requested training from local experts, community members, NGOs and government organizations for their projects. As we were not part of the integrated community, our major role was quickly reduced to soliciting resources and helping villagers connect with local resources and outreach groups.

5. Discussion

Developing income-generating activities through collective action proved very successful in each of the groups. Also, participant action required individuals to help themselves create self-reliance and teamwork. For example, in the Bukyaye village, the members of the group decided to build their own chicken coop with the little resources they had, utilizing their own materials and their own labor. When they came across a lack of funds for specific costly materials, they requested help and advice. At times, the best solution required they seek outside support to purchase materials, however, the bulk of the issues that arose involved troubleshooting through group discussions. Quite often, this led to a group member explaining how they could do it themselves through in-kind support. For example, polythane for

roofing and timber for framework were provided by group members and noted as their in-kind contribution. In Nawansinge, the clothing retail store needed shelving. A skilled carpenter within the group, John, provided the timber and labor to make the shelves. Harriet, a woman who had previously received vocational training in tailoring, offered to transfer her skills to other group members, both women and men, who expressed the desire to learn. Finally, those in Kinawanswa agreed to develop a communally-owned tool lending library where members all shared their farming tools. Group meetings and consistent member participation allowed the villagers to increase their capacity in order to uplift themselves collectively by transferring skills to one another and working together to build their projects at the grassroots level. Their collective action and teamwork added incentive to the success of each group's business enterprise. The groups came to the scheduled meetings, oftentimes missing out on important obligations such as work in their gardens or attendance at burials; this commitment added even more incentive and placed more value on the success of their group enterprises.

Providing educational lessons to each group on topics such as savings, investment, financial management, and bookkeeping, was vital and required the help of local community members and in-kind support from the community. In addition, educators, who were most difficult to access, provided lessons on modern farming methods, tailoring, and rearing poultry. Some educators requested significant payment for their services, indirectly reiterating the lesson that collective action and in-kind community support was a better way to help villagers expand their skill sets. Not only is such community support less expensive, but it also contributes a stronger sense of community. Educational services that were either low-cost or donated as in-kind support were key to creating a sense of community within the village and contributed to the likelihood of developing sustainable income-generating projects.

Finally, along with working directly with PWDs, we worked to raise awareness about disabilities. An assembly at Buckley High School, the first school in Uganda for deaf and/or blind children, was developed using Freire's theory of conscientization to raise awareness around disability amongst children, both "abled" and "disabled." This assembly sought to create "realization" regarding the plight of PWDs in Uganda. According to Freire, after achieving this realization, PWDs could potentially change their subordinate status through by becoming conscious of their oppression; he postulates that they can then use direct action to create social change. Buckley High School provided the platform that was necessary for IDIWA staff to influence the community as a whole and teach about disability, explain the importance of helping people with disabilities, and inspire others to overcome adversity. The assembly served as a pilot project that could be further developed and further integrated into other communities.

6. Conclusions

Though we hesitate to draw a causal relationship between conscientization and collective action, our research indicated that they are key ingredients in uplifting PWDs and improving their lives. Though the true impact of the projects we helped facilitate will require time to manifest itself, individual accountability is embedded within the nature of communal work. The beneficiaries of these projects have

developed knowledge, new skills, and strong relationships and have acquired significant material goods. In Bukyaye, there is now a chicken coop with fifty chicks that will produce eggs and chicks within two months; in Kinawanswa there are fourteen acres of un-harvested ground nuts that are scarce and valuable within the community; in Nawansinge, there is now a clothing retail store with significant amounts of merchandise with a detailed plan for expansion. All of these enterprises were created, developed, and will be maintained through the collective action of small communities with a unifying bond. These projects demonstrate how grassroots development could be used to improve the quality of life for PWDs. In Uganda, within the past few years, policies that attempt to help PWDs have been created. However, the impact of these policies can best be realized through group involvement. Daniel, UPACLED staff, stated, "Once you identify groups of people that need help, then, you can what? You can help them with what they need." PWDs need to be identified and this can only occur if they are organized at the grassroots level. Top-down measures can only produce a limited impact if the targeted beneficiaries are not mobilized on the ground and are not aware of the rights afforded to them and the potential resources available.

Although this paper only briefly touches on the plight of women with disabilities in Iganga and in similar rural communities, they face the double-edged sword of a patriarchal society attached to the cultural stigmas surrounding disability in Uganda. Further research must be conducted to determine mechanisms for women with disabilities to achieve upward mobility, particularly at the grassroots level.

People with disabilities are undeniably discriminated against throughout the world and, as in all types of aid and development work, those directly affected must be engaged in the discourse of their own development. During our research, PWDs repeatedly stated that "disability is not inability." This rang true throughout the development of the community-based projects we facilitated. Despite their nuanced and profound disabilities, the members of our groups were completely capable and effective in helping each other help themselves. Each member contributed and acted collectively to achieve a common goal. Development workers and aid organizations must consider these concepts in future development planning. Although top-down measures are necessary for development, grassroots participatory development and collective action can help marginalized people experience sustainable development on their own terms and through their own action and capabilities.